

# THE PENNHURST LONGITUDINAL STUDY

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combined report  
of five years of  
research and analysis



**EXECUTIVE SUMMARY**

# THE PENNHURST LONGITUDINAL STUDY

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3535 MARKET STREET PHILADELPHIA,  
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March 1, 1985

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Dear Colleague:

I am pleased to present you with a copy of the final report of the Pennhurst Longitudinal Study. This study was a five-year, in-depth review of the effects of the court-ordered deinstitutionalization of the residents of the Pennhurst Center, a state-operated facility for mentally retarded persons in Spring City, Pennsylvania. The aim of the study was to provide federal and state officials and others with information to make better policy decisions regarding the processes related to the deinstitutionalization which is underway in many parts of the country. Federal planners, recognizing the significance for clients, families, communities, and states of Judge Broderick's and other similar actions, decided in 1979 to launch this five-year study.

This project was unique in several respects; perhaps most importantly as a joint endeavor among the Region III Office of Human Development Services, the Assistant Secretary for Human Development Services, the Assistant Secretary for Planning and Evaluation, and the Commissioner of the Administration on Developmental Disabilities, as well as the Deputy Secretary for Mental Retardation in the Commonwealth of Pennsylvania.

The study has yielded considerable information which is not only valuable to other researchers, but also instructive to legislators, judges, and federal, state, and local program administrators and policy makers. It is for this reason that we are giving it wide distribution. The report also contains information on how to obtain additional copies or any of the detailed reports which comprise the study.

If you have any questions about the final report or the Pennhurst Longitudinal study in general, please do not hesitate to contact me.

Sincerely,

Eileen Bradley  
Regional Administrator

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# Overview



## Background of the Study

When United States District Court Judge Raymond Broderick issued his opinion in the **Halderman v. Pennhurst State School and Hospital** case in 1977, it was considered the most far-reaching legal event in the field of mental disabilities to date. Unlike other federal judges who had primarily focused their attention on the improvement of institutional settings, Broderick ruled that Pennhurst State School and Hospital was **incapable** of providing constitutionally appropriate care and habilitation. This finding led him to conclude that the residents of Pennhurst, those on the waiting list to the institution, and any other mentally retarded person in the community "at risk" of institutionalization at Pennhurst should be provided services in less restrictive settings in the community.

Following Broderick's ruling and the issuance of his decree in March, 1978, plaintiffs in 20 other states began the process of seeking similar relief. Recognizing the potential national significance of the **Pennhurst** case, leadership in the Department of Health and Human Services (DHHS) — specifically in the Office of the Assistant Secretary for Planning and Evaluation (ASPE), and the Region III (Philadelphia) Office of Human Development Services (OHDS) —decided to support a five year longitudinal study which would:

- measure the relative growth of residents in the institution and in the community in order to determine the impact of relocation on mentally retarded persons;
- assess the impact of deinstitutionalization on the families of retarded persons and on the communities in which they live;
- compare the costs of providing services in the institution to those in community settings;
- assess the legal history of the **Pennhurst** case;
- address significant issues growing out of the implementation of the district court decree.

The main value of the study has been its utility in providing DHHS, state, and court officials with information on which vital short and long term policy decisions can be made. From the initial conception of the project, the Pennhurst Longitudinal Study has been a partnership involving the Commonwealth of Pennsylvania, the court, ASPE, and OHDS Region III. Further, because of the information needs of the Office of the **Special Master** and the Pennsylvania Office of Mental Retardation, their representatives also participated in the original design and in the ongoing oversight of the project. In addition to direction provided by the DHHS project officers, the Pennhurst Study Work Group was also established to ensure the study's continued relevance. Members of this group included representatives of the Special Master, the Hearing Master, the Office of Mental Retardation, the Pennsylvania Developmental Disabilities Council, and the Region III Developmental Disabilities Office.

Further, in order to ensure the national relevance of materials emerging from the Pennhurst Longitudinal Study, an Advisory Committee was appointed. The Committee was comprised of national experts in the field of mental retardation, a representative of the national organization of state mental retardation commissioners, and others interested in the general area of litigation and deinstitutionalization.

The Longitudinal Study, which was conducted as a collaborative effort by the Temple University Developmental Disabilities Center in Philadelphia and Human Services Research Institute in Boston, is divided into three major parts:

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## The Pennhurst Longitudinal Study

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- **Impact on Clients and Communities** (Temple University)

This portion of the study involved monitoring the developmental progress of the study population, the services they received, the quality of their living environments, and the level of their satisfaction — both at Pennhurst and after relocation to the community. This segment also included an assessment of the impact of deinstitutionalization on families of clients, both in anticipation of the action to be taken under the decree and following the actual relocation, and the attitudes of others in clients' local communities both before and after deinstitutionalization. Included in this study component were case studies of several Pennhurst residents which provide a more in-depth exploration of the impact of the case on particular individuals.

- **Impact on Costs** (Human Services Research Institute)

The results of this portion of the study include an assessment of the costs and cost configurations of services provided both at Pennhurst and in community settings. For as many service categories as possible, average costs per unit of service at Pennhurst and in the community were calculated. These service unit costs were applied to the reported units of service received by individual clients. From this, the staff derived estimates of total costs for each relocated client, as a function of how much service the client actually received.

- **History and Implementation Analyses** (Human Services Research Institute)

This study area included a continually updated historical account of the implementation of the **Pennhurst** decree and the events surrounding the litigation for the first three years of the study. In the course of these assessments, the actions and intentions of policy makers were highlighted. Further, the interrelationships among events and key system actors are chronicled and the implications for state and federal policy were explored. In addition, four aspects of implementation were singled out during the course of the study for extensive investigation and analysis.

The following document is an executive summary of the findings and recommendations of five years of **work** in the above three research areas. Because a great deal of information has been summarized in a very short space, only the highlights of the study are captured. For the reader who is interested in more background on the methods and results, we strongly urge that you secure a copy of the final report for Year 5. The report, titled **The Pennhurst Longitudinal Study: Combined Report of Five Years of Research and Analysis**, includes the results of both the quantitative and qualitative analyses as well as the instruments used. The report is available from Temple University (the address is included on the title page). A list of the reports that have been produced in the past five years and the ordering procedures are at the end of the summary.

## Introduction to the Results

One purpose of the Longitudinal Study was to explore the use of class action litigation as a tool for the reordering of services to persons with mental retardation. A second and distinct purpose was to assess the implementation of an extensive deinstitutionalization activity, however initiated. In some ways, the qualitative policy analyses were a vehicle for fulfilling the first purpose while the quantitative studies carried out the second and equally important objective. After five years of analysis — an almost unprecedented **length** of time in social science research — the two purposes have meshed and intertwined as the qualities of the litigation have interacted with the process of deinstitutionalization.

In many ways, the richness of the study can be attributed almost entirely to the presence of the court decree — not just because the decree **required** the state to move mentally retarded people out of Pennhurst State Center into the community but because the litigation placed a spotlight on the system and speeded up the process of change. The spotlight of the lawsuit also made the process more self-conscious and apparent. All of this made it possible for the researchers to observe phenomena that otherwise would have been obscured by time and a multitude of confounding and contradictory factors. Like time-lapse photography, the litigation exposed the change process to the naked eye and made it possible to see both the strengths and weaknesses of community-based care in strong relief.

In the first part of the executive summary, we provide a synthesis of what we have learned. These findings are summarized as a prelude to the second part of the summary in which we apply these findings, to the extent scientifically permissible, to specific recommendations for federal, state, and local action.

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# Findings of the Quantitative Studies



The part of the Pennhurst Study that was conducted by the Temple University Developmental Disabilities Center/UAF was designed to answer just one major question: are people better off? That question has been approached in several ways, because well-being has many facets.

Before presenting a summary of the findings about the aspects of well-being that we have measured, a brief description of the kinds of people who lived at Pennhurst, and of the kinds of community programs that later became their new homes is helpful. Without knowing the characteristics of the people and the system we have studied, the reader cannot judge whether the results of deinstitutionalization for other people in other systems will be similar to ours.

There **were** 1154 people who lived at Pennhurst Center on March 17, 1978. Their average age was 39 years, they had lived at Pennhurst for an average of 24 years, and 64%. were male; 33% had a history of seizures, 13% had visual impairments, 4% had hearing impairments, and 18% were unable to walk. Life-threatening medical conditions were reported for fewer than 1%. Just over **50!?)** were nonverbal, 47% were less than fully toilet trained, and 40% were reported to display physical violence toward others. Among the people at Pennhurst, 86% were labeled severely or profoundly retarded.

The community service system was composed of residences called community living arrangements, or CLAs. They were very small, with the vast majority serving three individuals. They were almost always located in regular housing stock, and were staffed continuously when the residents were home. All were operated by private service providers under contract with county mental retardation programs, and counties received **100%** state support for the residential setting and 90% support for day programs. Every person left the CLA on weekdays to attend a day program.

## Individual Behavioral Development

Continual behavioral growth toward independence is a central goal of services for people with mental retardation. We have found, by every scientific design and test available, that people who have gone to CLAs are better off in this regard. They have made more progress than similar people still at Pennhurst, and more than they themselves made during their prior time at Pennhurst. These people have become more able to do things for themselves, rather than having things done for them. "Adaptive behavior" is a general term for this facet of independent functioning. The following graph shows the increase in adaptive behavior for 176 people who were living at Pennhurst in 1978 and 1980, and then in CLAs in 1983 and 1984.

The Behavior Development Survey, or BDS, our general measure of adaptive behavior, could range from 0 to 128 points. From 1978 to 1980, while living at Pennhurst, these people showed no significant increase in adaptive behavior. When they moved to CLAs they became sharply less dependent, and, considering the results of all our analyses, they generally **continued** to grow and learn after moving, at least for another year.

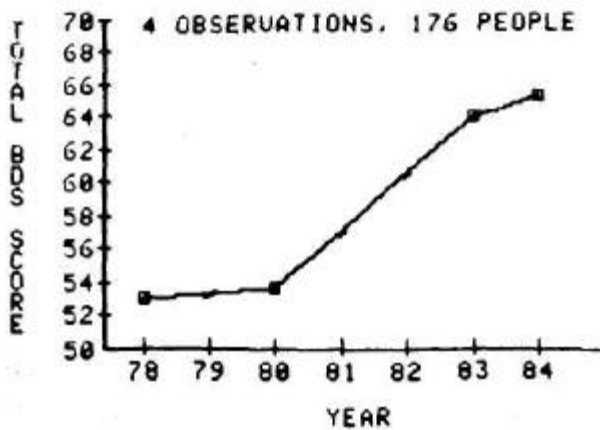
The final year of data, however, suggests that the rapid rates of behavioral progress have begun to level off. Evidence thus far is not sufficient to determine the cause; it could be that the system and its service providers simply could not sustain the high level of enthusiasm associated with such an unprecedented deinstitutionalization effort forever, or it might be related to the removal of the special independent court master, or perhaps real progress is still occurring but it is now in areas that our

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## The Pennhurst Longitudinal Study

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### ADAPTIVE BEHAVIOR GROWTH



behavioral instrument addresses only slightly (such as self image or comfort in integrated settings or specific vocationally oriented skills). In any case, progress has not stopped or reversed, it merely appears to have slowed.

We also find that the people who seem to make the greatest gains in adaptive behavior tend to be those who start out lowest. That is, the people with the most severe impairments turn out to be among those who benefit the most from community placement.

The adaptive behavior growth displayed by people who have moved to CLAs under this court order is literally ten times greater than the growth displayed by matched people who are still at Pennhurst. People at Pennhurst are not regressing — they are showing developmental gains, but at a far slower rate than people who move to community placements.

## Services Rendered

Do people receive the services they need after community placement? In the Pennhurst situation, there is a change in service patterns when people move to CLAs. The people who have moved to CLAs (movers) receive fewer hours of developmentally oriented service hours at the places where they live; about 104 hours per month compared to about 156 hours among people still at Pennhurst (stayers), but more day program service (about 121 hours per month compared to the stayers' 33 hours). Adding the two kinds of service, the movers receive more total hours of service (225 hours per month) than the stayers (189 hours per month). Hence we conclude that, on an overall index of amount of service, the movers are better off.

The evidence on medical services suggests that people in CLAs are, for the most part, using the Medicaid and Medicare services systems effectively, and we have observed few cases of people lacking regular checkups or other needed services. Moreover, we have seen no change in general indicators of individual health following placement.

We also find that the number of daily prescription medications to each person declines after community placement, and has also declined among the stayers. For both groups, then, we would infer that they are better off in terms of the risk of overuse of medications.

## Consumer Interviews — Satisfaction

In this part of the study, we interviewed a sample of people before and after they left Pennhurst. The sample is **not** representative of all the people who lived at Pennhurst, the majority of whom could not respond to a **verbal** interview. Nevertheless, we have learned a great deal by talking to people directly, both about **their own** feelings, and about the methodology of conducting direct interviews with consumers.

We interviewed a sample of 56 verbal people in 1980, while they were still at Pennhurst. We included check questions for each of the important questions, so that we could eliminate contradictory and inconsistent responses from the statistics. The 56 people were generally happy and satisfied with all aspects of Pennhurst. We found that 39% reliably said they wanted to stay at Pennhurst, and only 23% reliably said they would like to go live somewhere else. (The remaining 38% of the people were inconsistent or did not answer these questions.)

Thirty of the original 56 people have now moved and have been reinterviewed in their new community homes. Their responses show that they are significantly happier than they were at Pennhurst in most aspects of their lives. Twelve of these 30 people reliably expressed happiness about living at Pennhurst in 1980; now, 22 reliably say they are happy living in the CLA. The proportion of people who reliably want to keep on living in the CLA is up to 63% (from the 39% at the institution). There has been no decrease in any area of satisfaction or happiness.

## Findings of the Quantitative Studies

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Among the other 26 people who are still at Pennhurst awaiting placement, our 1984 reinterviews show no changes at all in satisfaction or happiness from 1980.

We have noticed a sharp increase in consistent answers from the first to the second interviews, both among movers and stayers. Having considered many possible explanations, we tend to favor the idea that these people, who had seldom been asked their opinions about important things, were at first unprepared and perhaps somewhat nervous. But the interview, which was indeed an unusual event in their lives, may have been the subject of much thought afterward. By the time of the second interview, they had actually clarified their own opinions about what they liked and how they wanted to live. This suggests that consumer input, if we will ask for it and listen to it, may become progressively more useful.

## Qualities of Environments

We have found that the CLAs are considerably higher on scales of normalization and individualization than were the living areas at Pennhurst. We therefore conclude that people are better off in terms of these two environmental qualities after moving from the institution to a CLA.

In our work on measuring environmental qualities within community residences (including physical comfort, 18 aspects of normalization, individualization, life safety, encouragement of autonomy and activity, size and staffing patterns), we have tried to shed light on what environmental qualities "make a difference" for individual growth and development. Our preliminary findings indicate that the degree of normalization of a community setting makes a difference, with people in more normalized settings making more progress. We also find evidence that size makes a difference, with people in smaller settings doing slightly better (even though the size of the settings only ranges from 1 to 8 people). The data also hint that, controlling for differences in the level of functioning of the people in the community settings, more regimentation may be associated with more growth. This tentative finding demands more investigation. In another analysis, we see a suggestion that settings with "too many" staff may produce less growth among the people living there — but we need long and careful scrutiny of what might constitute "too many" before saying any more.

Findings of equal or greater importance have arisen from unexpected quarters. **All** of the programmatically oriented measures we have used are rather highly correlated with the adaptive behavior of the occupants. This means that programs serving people with more serious disabilities will automatically receive lower ratings on these measures. That is not a desirable property for any set of environmental scales or standards.

Another unexpected finding of our work is that none of the environmental scales that were available for use in this study offered adequate reliability data, not even those that were in use on a national level. Moreover, during the course of the work, we came to suspect serious reliability problems with many of the environmental instruments we used. The Pennhurst Study was not designed to do large scale reliability checks of program standards and scales, but that is certainly an area for immediate and important work.

## Family Impacts

We now know from national studies that most families of people living in public institutions vigorously oppose the idea of community placement. The families of the people living at Pennhurst Center are no exception. The unique contribution of the Pennhurst study is that this is the first time families have been interviewed **before and after** community placement of their relatives.

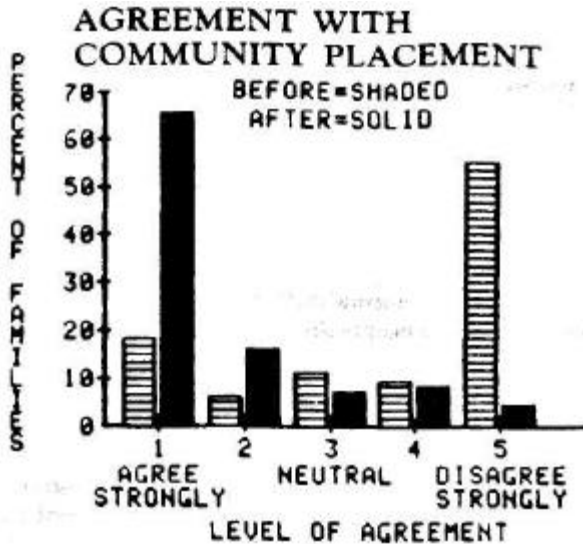
We found, in 1980, that 83% of the families of people living at Pennhurst expressed satisfaction with the institution, and 72% said they were unlikely to agree with any decision to move their relatives to CLAs. We also found that opposition to the CLA idea was **not** related to the relatives level of retardation. Moreover, families who had visited a CLA opposed them just as much as those who had not. In addition, we found that most families did not believe that their relatives were capable of learning any new skills, and we found strong evidence that many of the families had an exaggerated perception of the level of medical attention needed by their relatives.

In any case, we could comprehend the reluctance of the families to accept the CLA concept on the grounds of one fact alone: their relatives had already lived at Pennhurst Center for an average of 24 years. Change after so long is difficult for anyone.



## The Pennhurst Longitudinal Study

The family of each person who went to a CLA was reinterviewed six to 12 months after the move. A total of 134 families were interviewed "before and after." The changes in feelings about community residences are dramatic. The graph below illustrates the magnitude of our findings.



On the left side, the graph shows the increase in the proportion strongly favoring community placement, from less than 20% before to over 60% afterward. Conversely, on the right, we see that after placement, less than 5% of families strongly oppose the CLA option.

Survey results show that the families also perceive their relatives to be much happier after the move. There are significant and positive changes in practically every item on our survey.

In the areas of the relative's potential for growth and the perception of the relative's medical needs, however, the before-to-after changes are relatively small. We are continuing to watch these attitudes in Pennsylvania to see whether they will gradually change over years of community living.

Our data also show no substantial increase in family visits after community placement. It seems that the families who visited frequently at Pennhurst continue to do so in CLAs and vice versa.

In a nutshell, we have found that initial family opposition changes drastically to surprised and enthusiastic support of the CLA option, tempered by continued concern about permanence. Our perception of the single most important finding of our work with families, other than their delight with the new mode of care, is their continued and unabated concern for permanence. Few of the families are convinced and confident that the CLA model offers a sufficient "guarantee" that their relatives will have a safe and pleasant place to live for their entire lives.

**Neighbor Attitudes.** The long duration of the Pennhurst Study has enabled us to investigate neighbor attitudes in a way that has not been done before— interviews with neighbors of CLAs before and after the CLAs open.

We interviewed neighbors of eight planned CLAs about six months before they opened. This was before anyone in the neighborhoods knew of the planned CLA. We asked the neighbors how much they would be "bothered" if small groups of various kinds of people moved into a house in the area. The respondents said they would be bothered very little by new neighbors with physical disabilities, or with mild mental retardation, or of a different race. They admitted that they would be bothered a lot more by people with mental illness or severe mental retardation.

The potential effect on property values was a strong concern about new neighbors with mental illness, with severe **mental** retardation, and of a different race. This concern was much less intense about people with mild **mental** retardation.

In all, it **appears** from our data that only about 10% to 20% of neighbors would be opposed, on their own, to a small group home for people with mental retardation, depending on the level of retardation of the people. However, this situation can probably be changed by vocal leadership, even from a small number of strong opponents.

The same neighbors were reinterviewed about six months after the group homes opened, and then again at about 20 months after opening. We found that only 28% of neighbors were aware that a group home had moved in at all. Among the cognizant neighbors, there was a small but significant negative shift in their general attitudes about people with mental retardation — but this shift was visible only at six months after opening, and had vanished by the time of the 20 month interview. Thus we found a small and temporary negative reaction among neighbors of new group homes.

This temporary negative reaction is further documented by the fact that neighbors who knew about the group home told us that they had been much more negative when they **first heard** about it than they were **now**.

## Findings of the Quantitative Studies

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Finally, it appears that the opposition of average citizens to **imagined** group homes in their neighborhoods is considerably stronger than the **actual** opposition among neighbors of **real** group homes. This presents program implementers with a fascinating double bind: if a program opens in a community, opposition will decrease, but if the opposition is strong enough, the program will never open.

**Synopsis and Cautions.** The five years of the Pennhurst Study have led to the conclusion that, on the average, the people deinstitutionalized under the Pennhurst court order **are** better off in every way measured. This is an uncommon, but welcome, situation in social science. More often, evaluative results are mixed and one must balance gains in one area against losses in another. For the people who have moved from Pennhurst to small community residences, results are not mixed. They are conclusive.

Scientifically, this is not the end of the story. How do we know that deinstitutionalizations elsewhere would produce similar results? The answer is that we do not. Scientific conclusions are stated in probabilistic terms. The more a deinstitutionalization process resembles the one we have observed, the more **likely** it is that similar results will be seen. Any who wish to know if their efforts will obtain similar outcomes must understand the nature of the service system we have studied here, and be able to relate it to the nature of the system in their own area. To the extent that the placement process and the community service system are different, the results of deinstitutionalization may be different.

Similarly, to the extent that people in other community placement efforts are unlike the people in our study, the results of deinstitutionalization may be different from ours. Our study concerned people with very serious intellectual and other impairments. One must draw a careful distinction between the group we have studied and the people who were "deinstitutionalized" from facilities for people with mental **illness** (not retardation) in prior years. Some of those people were discharged with little more than a supply of medications to support them, and went on to join the ranks of the homeless who may be seen on streets and warm air vents in major cities. That was emphatically neither the kind of person nor the kind of process observed in the Pennhurst Study.

Though cautions against careless generalization are important, it is also scientifically important to stress that, in the Pennhurst deinstitutionalization, the measurable improvements in the lives of the people have been very great. Such gains make it clear that such outcomes are **possible** given similar circumstances.

It is also important to note that we have observed an unusual community placement process, in that 81% of the people who have moved to CLAs are labeled severely or profoundly mentally retarded. That simple fact definitively invalidates the notion that community care for people with severe or profound mental retardation cannot work.

## The Costs of Serving People at Pennhurst and in Community Programs

The Human Services Research Institute completed an extensive and direct collection of cost information for 42 living areas at Pennhurst and 102 community residences, four adult day programs at Pennhurst and 35 in the community, specialized support programs at Pennhurst and in three of the five counties, case management at Pennhurst and in each of the five counties, and also for medical and transportation services. In addition, data on staff activity patterns were collected for all areas by direct structured interviews.

Three unit cost measures were employed: (1) cost per person per day, (2) cost per hour of direct care staff time, and (3) cost per hour of selected specialized developmental service. For all three unit cost measures, the community residential programs were found to have a wider range of costs that were lower on the average. The greatest unit cost differential was in the cost per hour of direct care staff time, for which CLAs expended on average only about 40% of the amount expended at Pennhurst.

Of equal importance was the finding that the largest part of the difference between CLA and Pennhurst residential program costs could be traced directly to differences in staff salaries and benefits. At Pennhurst, the employees were state civil service workers, and were almost entirely unionized; they earned an average of 30% more than their community counterparts, who were employees of private corporations and almost entirely non-unionized. The Pennhurst employees also enjoyed an overall fringe benefit rate of 63% of salaries, double the rate of community workers.

For day programs, the community settings showed somewhat lower costs per person day, but considerably higher costs per hour of direct care staff time. The community day programs showed much higher costs for indirect functions, such as drivers and food service workers. For specialized support programs such as behavior management, the relative costs in institution and community were higher or lower depending on what services the programs were defined to include. In the remaining program areas (case management, medical, and transportation), the cost finding procedures were not exact enough nor the number of programs large enough to yield definitive findings.

Our general conclusions must be tempered by the fact that we have studied a system under somewhat unusual conditions. The court order is one unusual condition, but it is also important to note that the cost environment in general is not typical of the country. Pennhurst Center itself has become very costly during the years after the court order, in fiscal 1981-1982, the Pennhurst per diem cost was \$123, compared to a Pennsylvania institutional average of \$108 and a national average of \$93. The surrounding CLAs are also high in cost, with an average per diem of \$91 for the people who formerly lived at Pennhurst, and \$63 for people who were never at Pennhurst. Both of these rates are more than the state average of \$49, and more than the national average of \$39.

One might say that what has been compared here is a relatively expensive public institution affected in some part by a federal court order and a relatively expensive private system of community living arrangements and day programs also affected to some degree by a federal court order. The general conclusions below are offered as the findings that we think are most **likely** to be generalizable to other areas and situations, but the less a system resembles the Pennhurst situation, the less likely that the cost conclusion will be applicable.

First, the analyses indicate that the community based programs now serving the people who formerly lived at Pennhurst are less costly on average than those at the institution in terms of most cost measures. The cost differential can be traced almost entirely to differences in salaries and fringe benefits between the state employees at Pennhurst and the private employees in the community programs.

Second, we believe our findings of generally higher salaries and fringe benefits for employees of state institutions than for employees of community residential and day programs hold true in **most** states. This suggests that our findings of generally lower costs for community programs is probably true for many other areas of the country.

Third, because most of the savings arise from what seems to be marked pay differences, we conclude that the savings may be temporary. Over the long run unionization and other such forces may lead to a more equitable situation and thus reduce and/or eliminate the cost differential.

Fourth, the cost differentials were larger when cast in terms of the cost per hour of direct care staff time than in terms of cost per person day. Therefore advocates wishing to promote community programs are probably best advised to cast their arguments in terms of "getting more direct care staff time for the dollar" than the overly simplified "community programs are cheaper" rationale.

Fifth, some "out-of-pocket" savings that were documented are inherent in smaller community based programs. People living in community based programs can utilize the same generic services (e.g., religious, **library**, fire safety) offered to every other citizen, and the cost is spread over a much larger number of **people**.

Sixth, **the** data indicate that there may be no economic advantage associated with the specialization of labor in **large** institutions like Pennhurst. Normally, specialization is expected to enhance efficiency and productivity, but, in this kind of human service organization, the opposite may be true. Employees of community programs appear to be generalists, handling many kinds of activities that at Pennhurst are assumed by personnel who are hired and trained to do nothing but that function (e.g., guardianship, food service, housekeeping, laundry). Community residential program staff even go so far as to implement physical, occupational, speech, and behavioral therapies designed by consultants at low cost.

Seventh, the relationships found between the characteristics of individuals and the costs of the community programs serving them are relatively weak. This seems to indicate that people are often being fit into programs, rather than programs being designed specifically to meet individual needs. This is contradictory to one of the implicit aims of small, more individually tailored residential and day programs.

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# Findings of the Qualitative Studies



## Implementation Issues

The Human Services Research Institute conducted four implementation analyses: the role of the Special Master, the response of the defendants to the litigation compared to the reaction of other states, factors affecting the implementation of court decrees in Pennsylvania and in four other states (Maine, Michigan, Minnesota and Massachusetts), and the impact of the **Pennhurst** case on the mental retardation system in Pennsylvania.

## Office of the Special Master

In order to provide a comprehensive picture of the Office of the Special Master (OSM) in **Pennhurst**, this analysis encompassed both the legal context within which the Master functioned and the larger political and organizational milieu that were the object of the court's intervention. The Office was also assessed in light of the experience of other masters and monitors in related litigation. The analysis drew both from the legal literature on complex litigation and compliance mechanisms, and from political science and public administration literature on implementation and program change. The assessment also included structured key informant interviews with officials in Pennsylvania and in other states. There were six factors that explained the character of OSM as well as its strengths and weaknesses as a vehicle for bringing about change.

**Lack of Consent.** The fact that Judge Broderick could not persuade the parties in the **Pennhurst** case to negotiate a consent decree had an impact on the remedy. In the absence of consent or of any proposed orders from the defendants, the character of the initial decree and of subsequent orders was significantly influenced by the plaintiffs. As a result, the defendants viewed OSM as intrusive since they had little stake in the remedy that OSM was empowered to implement.

**Limited enforcement powers.** Given the problems of other court appointed monitors in institutional and deinstitutional litigation, the plaintiffs in the **Pennhurst** case recommended a remedy that embodied comprehensive programmatic and compliance duties. The ability of the Master, however, to enforce compliance with the decree was hampered because of the limited sanctions available to the court. The only real sanction is the contempt power which, in cases like **Pennhurst**, is generally regarded as a last resort — in **part** because it must be directed at an individual or individuals. The court has no bonuses or **rewards to hand** out to compliant defendants except the ultimate disappearance of the court and the master from the scene once the aims of the decree have been fulfilled.

**Involvement in individual cases.** The Special Master's compliance functions reflected a broad and deep involvement in the day-to-day implementation of the decree. The Master's responsibilities began with class members in the institution, carried through the initiation of individualized habilitation plans, and continued through placement in the community. In short, OSM's compliance functions touched on almost every aspect of the traditional delivery system for mentally retarded individuals.

The client-specific nature of the remedy in **Pennhurst** was a significant factor in diverting the attention of the Special Master from the broader structural aspects of the decree. Involvement in individual cases siphoned off energy and placed the master squarely in the middle of debates reflecting conflicts in professional judgment.

Separate **and** countervailing agency. The establishment of OSM as an agency separate and removed from state and local government was directly motivated by the plaintiffs' frustration with the

defendants' past performance. Such isolation from the ongoing system, however, has drawbacks. In the case of the Office of the Special Master, the isolation and separateness of the agency created conflicts and tensions because of its perceived favored position and because it ultimately had to rely on state and local government to carry out the specifics of implementation. Establishing a working relationship with the defendants was difficult for OSM. Part of the problem was that OSM staff were perceived as being highly ideological. Though in fact many of the Master's staff had worked in the system, their separation from the system, and the rigid court-ordered procedures and time tables included in the decree conspired to create a picture of OSM staff as zealots.

These various structural and political factors created a "we-they" mindset in OSM and among the defendants. The feelings at OSM were the result of its continually frustrated attempts to influence implementation. The attitudes of the defendants were the result of their increasing alienation from what they saw as a "foreign" agency with power to direct their actions yet totally outside of their control.

**Lack of control over policy making.** Though the Master had a quasi policy making function in that she suggested proposed orders and devised related rules (e.g., individual habilitation plan guidelines), she was not a policy maker in the strictest sense. The sources of broader policies that affected the system were the Governor, the Department of Public Welfare and the legislature. The separation of policy making from operations weakens the viability of any complicated activity. The need for linkage and coherence between policy and implementation is as relevant in court-ordered change as it is in legislative or bureaucratic change.

**Lack of an overall plan.** The court order did not specify that the Master was responsible for developing an overall plan to guide implementation. OSM was given the responsibility to develop separate county plans that included the specific clients to be served, the resources necessary, and the types of services that would be required. OSM and others argued that the development of such plans should be left to county program staff. However, county staff in particular voiced the need for an overall plan that spelled out the expectations of the Master including the schedule of implementation and specific actors designated to carry out particular tasks.

## State Response to Litigation

The response of states to litigation has been varied and wide-ranging. Even within a particular state, the official position can shift in response to changes in the level of resources, the force of public opinion, a turnover in political leadership, and pressures of competing constituencies. Some states readily entered into consent agreements with plaintiffs. Some states, even after consent agreements were signed, resisted the court's jurisdiction. Still other states, like Pennsylvania, continued to contest the court's right to intervene in the state system. The purpose of this implementation was to explore the factors that dictated Pennsylvania's reaction as well as those of other states facing complex litigation.

The analysis was based on key informant interviews in Pennsylvania, Maine and Michigan as well as on a review of the legal literature and the literature on legal theory. The analysis aimed at factors affecting consent and non-consent, and factors influencing progress in the implementation of court decrees. It should be noted that no one factor can be isolated as necessarily the most prominent given the complexity of court-ordered change.

**Factors associated** with consent and degree of implementation. Ten potential hypotheses were developed in order to explain state reactions.

- **Level of sophistication and development of the existing state mental retardation system** — This factor did not prove very helpful in explaining the distinction between Pennsylvania on the one hand and Maine and Michigan on the other. Though Maine's system at the time of the suit was not fully developed, the Michigan system was clearly mature and sophisticated
- **Extent of public pressure for reform** — In Michigan, the pressure generated by the press and from the public facilitated consent. In Maine, the pressure was unfocused and in Pennsylvania the pressure was more sporadic. This factor may be a partial explanation for consent but does not necessarily explain progress once the agreement is reached.

- **Explicit or implicit agenda of state officials** —This factor appeared to be important both with regard to consent and progress in implementation— a fact that is born out in the comparison states and in the literature. To the extent that state officials see litigation as a means of furthering their programmatic agendas—which Pennsylvania did not—the chances of consent and progress are heightened.
- **Orientation of the state's political leadership** —This factor has a somewhat vague relationship to the events analyzed. If orientation means political party, there appears to be no relationship between party identification, and inclination to settle. In Pennsylvania, the case spanned two administrations, and neither settled the case.
- **Nature of the relationship between state program officials and state lawyers** — This factor appeared to be important in forging a consent decree. In the two comparison states, state lawyers were more influenced by the agenda of state mental retardation program officials than was the case in Pennsylvania.
- **Extent of previous litigation in the state** — Though it cannot be directly shown that the cumulative effect of multiple suits in a state will eventually turn state officials against consent decrees, anecdotal information clearly suggests that enthusiasm wanes and wariness increases after prolonged experience with complex consent decrees.
- **Judicial strategies employed by the federal judge in contested and uncontested cases**—This factor requires more exploration. At least tentatively, it does appear that judges in Maine and Michigan were more successful at cajoling the parties into consent and into fairly regular progress. Other factors, however, may have influenced the behavior of the parties.
- **Nature of the decree and the monitoring mechanisms established** —This factor led to a circular argument that was not useful in explaining the differences among states. Since the nature of the decree and the compliance mechanism are directly related to whether or not there is consent, the analysis becomes a tautology.
- **Strategies employed by the plaintiffs** —This factor has potential utility for explaining the behavior of state defendants, but the limited amount of information in this analysis is not conclusive. If the defendants' perception of the lawyers themselves are taken into account, then this factor plus the strategies employed tended to create the opinion among the defendants in Pennsylvania that the plaintiffs' lawyers were implacable.
- **Level and distribution of state resources** —This factor was not particularly satisfactory in explaining the decision to consent among the three states—at least at the time such decisions are made. Michigan's level of funding was lower than what was available in Pennsylvania and the economic picture was more precarious. Level of funding may, however, bear on the decree of progress a state is able to make in implementing the
- decree.

**Other factors.** Though Pennsylvania was treated as an exception to the trend of settlement in mental retardation cases, the response of the Commonwealth may increasingly become the rule. The question is whether settled cases, if they were brought now, would result in consent agreements. Of the cases brought recently, more are going to trial, and consent agreements are more aggressively negotiated by the defendants. **Many state** officials are increasingly reluctant to submit control over aspects of the service system to federal court oversight. In part, this reluctance stems from direct experience with other consent decrees and in part from a feeling that the price paid for consent is not worth the benefits.

Further, resistance to federal court intervention was strongly influenced by the gloomy financial picture that emerged at the federal level and in several states. As long as resources were relatively flexible, there was enough "play " in the system to accommodate comprehensive consent agreements. As resources became short, meeting court requirements was seen as coming at the expense of the rest of the system.

Another related fiscal issue had to do with the Medicaid program. Those states that certified a significant number of institutional beds for Title XIX reimbursement may resist court -mandated deinstitutionalization unless they can be assured that the Title XIX funds will follow the clients into the community. In states where community programs are funded primarily with state dollars,

deinstitutionalization will result in a direct loss of federal funding and a concomitant drain on scarce state funds.

## Factors Affecting Complex Decrees

The purpose of the third implementation analysis was to ascertain whether those factors that had emerged in Pennsylvania as major influences on the implementation of the decree were present in four other states that were operating under a major lawsuit — Maine, Michigan, Minnesota and Massachusetts. The four factors were: the nature of the compliance mechanism, union opposition, legislative backlash, and parental resistance. In order to gather information for the analysis, key informants in Pennsylvania as well as in the four comparison states were interviewed, relevant court and state policy documents were reviewed, and the legal literature was explored.

**Legislative backlash.** As implementation of the court decree in Pennsylvania began, the legislature also intensified its scrutiny of the mental retardation system. Though in the past the legislature had, within reason, relied on the Department of Public Welfare to set the tone and direction for the mental retardation program, insistent complaints from parents and others stimulated the legislature to conduct its own investigation of the management of the system. Late in 1982, the Pennsylvania Senate passed a resolution establishing a five member investigation committee to review the operations of the Office of Mental Retardation. The committee looked into allegations of mismanagement within the Office of Mental Retardation, and in the community system in general. Though the work of the committee did not result in any change in state policy or state personnel, it did draw attention to a crack in the legislative consensus regarding community programs.

In each of the four comparison states, legislators were supportive of services for mentally retarded persons and did not appear to question continued development of community-based services. These legislators, however, all shared a certain restiveness about the continued presence of the federal court in the management of state mental retardation programs.

**Union influence.** In Pennsylvania, the American Federation of State, County and Municipal Employees (AFSCME) is a significant actor in the political arena in the state. Actions taken by the union in opposition to deinstitutionalization have included the use of litigation to attempt to block institutional closures and institutional phase-downs; financial support for the Parent/Staff Association, a defendant intervenor in the **Pennhurst** suit; and legislative lobbying, including successful opposition to zoning legislation that would have opened up residential neighborhoods to small group living arrangements for mentally retarded persons.

The nature of the litigation in the four comparison states was different in that the remedies were not solely oriented to deinstitutionalization. As a result, union opposition was muted. In three of the states, the unions benefited because the remedies resulted in substantial institutional improvement. In one state, where the institution was ultimately closed, the union did not oppose the phase out since conditions at the facility and abuse among the staff had been highlighted in the media.

**Role of enforcement mechanisms.** The creation of the Office of the Special Master in Pennsylvania, as noted in the first implementation analysis, caused a great deal of consternation both because of **the extent** of its responsibilities and the amount of resources devoted to its operations. The situation in **the four** comparison states, however, was very different. For one thing, the litigation in all of the states visited was settled by consent agreement. As a result, the court-appointed officers in the four states had responsibilities that were much more removed from the day-to-day operations of the system and the resources at their disposal were also more limited.

Given the numerous factors that influence the ability of a court appointed official to affect change, it is difficult to point to any one variable as more predictive of outcome than any other. All in all, those court monitors and masters that were most widely accepted by key system actors tended to avoid center stage and to limit their activities to more narrow compliance issues. However, those court officials that inserted themselves into the process clearly expedited implementation of the decrees — particularly in the early stages. This may suggest that different orientations and personal styles are required in different types of litigation and in different phases of a particular case.

**Parental opposition.** The **Pennhurst** litigation appears to have exacerbated if not created tensions among the parents of mentally retarded persons in Pennsylvania. Because of the frank deinstitutionalization character of the remedy, pro-institution parents were forced to take sides and they ultimately formed a separate organization and became opposing parties in the case. Given the community orientation of the Office of Mental Retardation in Pennsylvania, this polarization may have occurred in any event, but perhaps not as quickly nor as intensely.

One of the factors in Pennsylvania and in the four comparison states that appears to have a positive influence on the attitudes of parents toward broad scale litigation is the presence of an escape valve in the decree — either the ability to return a class member to an institution when necessary or the ability of parents to influence the nature and timing of placement. The **Pennhurst** decree, included no such escape valve (until the establishment of the Hearing Master) and the polarization of parents may have been one by-product. Family involvement also plays a role in parental attitudes especially when personal contact is made with families to reassure them and to explain the process. Overall, it is clear that parents are concerned about permanence and stability regardless of the nature of the suit. In deinstitutionalization cases, however, these feelings and perceptions become a major key to parental acceptance.

## Impact on the State Mental Retardation System

The final implementation analysis assessed the short-term and long-term impact of the litigation on the mental retardation system in Pennsylvania. In addition to a look at what has happened to clients and to costs—two areas covered earlier—the analysis focused on the impact on funding, the service system, Pennhurst State Center, and on state policy. .

**Funding.** Because data on funding by region was not available before 1980-1981, it was difficult to determine whether funding for the **Pennhurst** decree came at the expense of programs in other parts of the state. What is clear is that the Southeast Region of Pennsylvania has significantly higher per diem rates for community living arrangements than other regions and has a higher growth rate in CLA beds, but the region is a distant second in CLA beds per capita. With respect to federal funding, the litigation was only a partial stimulus to the development of small ICF/MRs in the community. Other factors, such as the need to "run-down" the census at institutions statewide, seem to have been greater motivations. The litigation does appear to have been a spur to the application for the community services waiver under Title XIX.

**The service system.** The litigation does not appear to have constrained deinstitutionalization in other parts of the state. It certainly has, however, hastened the development of community services in the Southeast Region. The litigation also appears to have contributed to increases in waiting lists in the Southeast Region (but not in other parts of the state) because of publicity surrounding the lawsuit and concentration of resources on class members. Finally, the litigation has certainly forced providers in the Southeast Region to develop a level of skill and capacity beyond what they would have under normal circumstances. Some providers, however, are beginning to show the strain of rapid expansion and long-term stability is a concern in some instances.

**Pennhurst State Center.** In the initial stages of the litigation, Pennhurst was insulated by the litigation from cutbacks made at other institutions. However now that closure has been announced, conditions have changed and the enrichment experienced during the period after the decree will almost certainly begin to recede.

**State Policy.** The litigation does appear to have had a permanent impact on state policy — especially in the areas of quality assurance, case management and individual client planning.

## Discussion

Based on the implementation analyses and the six historical overviews prepared during the course of the study, there are some general observations that can be made about litigation and the process of deinstitutionalization. First, it is clear that making family members a significant part of the



deinstitutionalization **process** is crucial to a smooth and successful transition to the community. The court-mandated **Hearing Master** process showed poignantly the need that family members have to voice their anxieties, concerns, and hopes for their relatives. Persons interviewed in the state acknowledged that allowing families to advocate for the interests of their relatives resulted in stronger more responsive placements for class members. In many instances, the hearing process was the first time that some parents had been able to face professionals as equals and to have their views treated with respect.

Second, community based agencies can develop the capacity to serve more disabled persons and can expand to serve increased numbers of mentally retarded persons. This achievement however, may also bring with it changes in the character of the community system. For one thing, the more the system expands, the more bureaucratic it becomes. Further, expansion also may tend to force out smaller providers that do not have the financial and administrative capacity to grow rapidly. Thus, though capacity is enhanced, some of the more attractive qualities of the burgeoning community system (e.g., sense of mission, spontaneity, etc.) may be jeopardized.

Third, mental retardation program officials cannot carry out the complex transition from institutional services to community-based care without a variety of financial supports within the state (e.g., from state Medicaid officials, income maintenance personnel, and vocational rehabilitation officials) and at the federal level.

State officials need federal support to carry out comprehensive deinstitutionalization activities. The **Pennhurst** case in particular provided the most dramatic example of the potential benefits of a state and federal partnership to accomplish responsible deinstitutionalization and the most disappointing outcome of attempts to forge such a partnership. Specifically, the state's plans for the conversion and development of small ICF/MRs were delayed and constrained by complexities in the federal regulations. The state's proposal to use the community services waiver under Title XIX to close Pennhurst and to place residents in community alternatives has still not been approved by the Health Care Financing Administration after months of negotiations and resubmissions. Without the approval of the waiver, the schedule proposed by the state for the closure of Pennhurst will be severely affected.

Fourth, it is obvious from five years of observation that the system infrastructure including quality assurance, monitoring, advocacy, case management, and individualized planning is crucial to the viability of residential and day services for persons with mental retardation.

Fifth, leadership in the **Pennhurst** case, as in nearly any field of human endeavor, critically influenced the way events unfolded. In this case, certain leaders appear to have exerted a dominant influence on the way the service system evolved and the capacity that was developed. The attorney who filed the lawsuit in 1974 and the attorneys for the Pennsylvania Association for Retarded Citizens were powerful forces for reform. Without their ten year commitment to this case, the dramatic improvements in peoples' lives that were documented in this study might have taken longer to achieve.

The remedy crafted by the federal district court judge made it possible to show that better lives for mentally retarded persons **could** be secured in the community. Further Pennsylvania's Deputy Secretary for Mental Retardation since 1980 brought experience from the Willowbrook litigation in New York State to bear on implementation of the **Pennhurst** decree. Her commitment to community programs has been reflected in policy **and** fiscal priorities, and it is largely as a result of her voice within state government that the Department of Public Welfare announced the eventual closure of Pennhurst Center. Finally, the persons serving as **Special Master** and **Hearing Master** brought unique expertise and force of personality to their respective roles. Together, they had a direct influence on the quality of the court protections and procedures developed pursuant to the decree.

Based on the Longitudinal Study's more recent qualitative and quantitative findings, what can we predict about the future of the mental retardation system as the court's presence recedes? As the study concludes, qualitative as well as quantitative findings indicate that the system established by the court is slowly reverting to a state of entropy as the energy and drama that surrounded the case begins to dissipate. The services that were created for class members, although still distinguishable in quality and intensity from the rest of the system, are increasingly subject to the same external pressures and strains as the rest of the system.

Clearly no reform effort, whether brought about through litigation or other means, can maintain momentum and a sense of renewal indefinitely. Complex systems will only tolerate change for discrete periods of time before organizational forces begin to blunt the edges of such change and accommodate the

## Findings of the Qualitative Studies

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**reform into the larger political, social and administrative context. Thus, on the one hand it appears that the intensity of reform cannot be sustained given the organizational needs for stability and predictability. However, the Pennhurst experience shows that when the impetus for reform diminished, the system had moved to a distinctly higher plateau.**

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# Recommendations



Both the quantitative and qualitative results of the Pennhurst Longitudinal Study provide guidance to future policy making at the federal as well as state and local levels, and also should be useful to local private service providers, the courts, advocacy groups, and others concerned with the development and improvement of programs for developmentally disabled persons. The recommendations that we feel flow from our work are presented in the following areas: Funding and Fiscal Policy, the Design and Administration of Community Service Systems, Capacity Building, the Role of Courts, and Quality Assurance and Monitoring.

Before presenting our final recommendations, however, there is one general statement that should be made that grows out of both the quantitative and qualitative studies — there is an overriding need for the development of a coherent policy on deinstitutionalization at the federal level. Though the General Accounting Office made a similarly strong recommendation in 1977, the results of the **Pennhurst** study suggest that, though some steps have been taken in the interim, federal policies still remain contradictory and place severe constraints on those states attempting to develop more responsive and cost effective community-based systems of care. If adopted, many of the recommendations below —particularly those aimed at the Title XIX program, would provide a consistent and purposeful federal agenda for the improvement of the lives of persons with mental retardation.

## Funding and Fiscal Policy

1. The sum of our quantitative and qualitative work leads us to a strong recommendation at the federal level regarding the use of Title XIX Medicaid funds for Intermediate Care Facilities for people with Mental Retardation or ICF/MRs: **access to ICF/MR reimbursement for institutional and community settings should be at least equalized.**

Our data are powerful enough to suggest **increased** federal incentives for non-institutional care. However, such statements may not even be necessary. The data on individual growth, services, environmental qualities, family reactions, and public costs combine to suggest that, if ease of access and reimbursement rates were equal, state officials would quickly see the payoffs of shifting to community-based service systems. Some advocates argue that Title XIX funding should be dramatically reduced in institutions in favor of community programs. We leave that balance to the political process and stand with our inference that ease of access and reimbursement rates should be made **at least** equal.

2. The regulations for small ICF MRs were not suited to the design of the Pennsylvania community system, and impeded the successful utilization of the program. For a state with a system like Pennsylvania's, with a large number of relatively small service providers, the need for large capital outlays for construction or renovation eliminated many of these agencies at the outset. The medically-oriented character of the regulations was also a disincentive in that conversion of existing CLAs was likely to result in a more hospital-like and less normal atmosphere. **Therefore, we recommend a liberalization of existing regulations to preserve the home-like character of small facilities and to ease access to the program among small providers.**

3. The potential availability of federal funding under the Home and Community Based Waiver Program (PL 97-35, Section 2176) became a major affirmative factor in the final settlement of the **Pennhurst** lawsuit. Yet the most recent revisions of the suburban county waiver applications, designed specifically to facilitate the closure of Pennhurst and the creation of less costly alternatives in the community have been rejected by the federal Health Care Financing Administration (HCFA). If Pennsylvania cannot secure federal approval to transfer Title XIX funding from Pennhurst as class members move to the community, we think that placements of those remaining at Pennhurst will slow or stop. Despite a commitment to close Pennhurst by June 30, 1986, the Commonwealth will be very hard-pressed to find the money needed to fund the 100% state funded CLAs. **We strongly recommend that administration of the community services waiver be made consistent with the original congressional intent to provide cost-effective alternatives to long-term institutional care. Further, HCFA should give special consideration and impetus to uses of the waiver program in those states, like Pennsylvania, that are pursuing a significant restructuring of all or a portion of the service system.**
4. Based on our cost study and our knowledge of other states, it is clear that federal Title XIX reimbursement is essential for any continuation of the trend away from segregated care for people with mental retardation. Our work on qualities of environments, in turn, suggests that the current ICF/ MR standards are largely inappropriate for very small community-based programs. To state officials we recommend that, in the absence of significant revisions in the ICF/ MR program recommended in #2 above, efforts should be made to avoid attempts at restructuring small group homes to fit the medically oriented standards of the ICF/ MR program. The design and structure of community-based service systems should not be unduly influenced by carryovers from the service model that is being supplanted. **Thus, we recommend a deemphasis of the so-called 4 to 15 beds ICF/MR program in favor of the more flexible waiver program.**
5. As community services become more mature and represent a more significant part of the total mental retardation system, the issue of staff salaries and parity between state and community staff will have to be faced. If the aim of the community system is to provide a stable living environment for mentally retarded persons with a range of disabilities, then **community staff should be paid at a level that will ensure the recruitment and retention of qualified personnel.**
6. Because our cost analyses showed that community-based care was less expensive than Pennhurst, but that nearly all of the difference was caused by lower wages and benefits for community program employees, **we recommend that administrators and advocates at all levels avoid the claim that tax dollars can be "saved" by switching to community-based services.** If the above recommendation is implemented, costs for serving similar individuals in the two settings will become nearly equivalent. However, for people and systems similar to the ones we have studied, we predict **that the value (i.e., the amount and quality of service rendered versus the amount spent) will still favor community-based care. We therefore recommend substitution of this latter point in place of the primitive and misleading "saving money" argument in policy debates.**

## The Design and Administration of Community Service Systems

The quantitative and qualitative research in Pennsylvania leads to several clear implications for the organization of service systems. Most are relevant to state officials and local program implementers, although some of the implications are also aimed at the federal level.

1. As noted in the introduction to this section, **a clear federal policy on deinstitutionalization is imperative to facilitate the orderly development and expansion of community-based care.** Such a policy should apply across agencies and

departments and should influence system design issues in income maintenance, housing construction and rent subsidy, medical services, long-term care, and social services.

2. The choice of funding streams is overwhelmingly important to the design and character of community service systems. For Pennsylvania's system of very small community living arrangements (CLAs), the ICF MR "four to 15 beds" program had several serious drawbacks. Nearly all of Pennsylvania's CLAs served just three people, and court cases in the state had established that settings with "three or fewer unrelated individuals" required no zoning variance in order to operate. To operate programs of four to 15 beds, however, many providers for the first time were forced to ask for zoning variances. Many facilities never opened because of neighbor opposition. **We therefore recommend that the lower limit on ICF/MR beds be eliminated in order to stimulate the development of smaller, more normal living arrangements.**
3. The interviews associated with qualitative analyses strongly indicate that state mental retardation program officials cannot carry out complex system change without the cooperation of other state generic agencies including Medicaid, income maintenance, social services, housing, vocational rehabilitation and labor. **We recommend that cooperation with other agencies in the form of cooperative agreements, should be secured as early in the planning for deinstitutionalization as possible.** Issues to be dealt with include the participation of mental retardation officials in the certification of community programs for Title XIX, input into the rate-setting process, availability of responsive day programs, use of state construction funding, state supplementation of SSI benefits, and use of social services block grant funding.
4. The qualitative analyses further indicate that **inter- and intra-agency planning at the state level is crucial to the success of any comprehensive deinstitutionalization activity.** There must be a commitment to such planning at the highest level of the state's human services agency in order to ensure a commitment of staff and resources to the process. Further, inter-and intra-agency planning should have a direct connection to funding sources and the development of community capacity.
5. Our qualitative analyses show that deinstitutionalization of a state facility usually implicates communities beyond a particular service area. **Therefore, we recommend that regional planning be initiated to ensure an equitable allocation and maximization of scarce resources such as specialized medical care and behavioral expertise.**
6. **Our observations of the process of deinstitutionalization in the Pennhurst case lead to our recommendation that implementation is best managed by a team of individuals who report directly to the state mental retardation program official and who are freed from other agency obligations.** The Pennhurst Implementation Team, which functioned in this fashion, proved invaluable to the success of the process.
7. Our study of the feelings of families in the deinstitutionalization process leads us to recommend that **any good community or institutional service system should provide a clear and meaningful role for the families of people (particularly adults) with mental retardation.** This sounds elementary, but it is far from easy to achieve. The courts have been in turmoil about the rights of the parents of adults who live in **settings supported** by public money. Are the parents automatically to be accorded the status of legal guardian? Must every adult with mental retardation be taken to court to be judged incompetent before a guardian can be appointed? Should parents or other family members have the power to veto community placement?

In the Pennhurst situation, family veto power would have precluded community placement for 72% of the people at Pennhurst, and would thereby have prevented the vast improvements in well-being that we have measured. **We must therefore recommend to state legislators, state officials, and local program providers that total control of the lives of adults under public care should not be ceded to parents or other family members. Rather, the design of service systems should clearly and formally assign a valued role in shared decision making to families, on an equal**

**footing with professionals and others involved in care.** This idea is already embodied in most processes of "individual habilitation plan" development under the court order.

**In addition, recognizing their special role, families should have a special appeal process available to them.** Comparable to "due process" hearings required by laws governing education of children with handicaps, such hearings should be prepared to deal especially with concerns about medical care, the possibility of continued growth and development, and security and permanence of any residential placement. In the **Pennhurst** case, a court-appointed Hearing Master conducted proceedings in which the concerns of families were treated with dignity. Most observers agree that the hearings had a strong positive impact on the confidence and peace of mind of the families.

8. Our experience with the consumer interviews indicates that local service systems will benefit from structurally increased opportunities for consumer participation. This goes beyond encouraging consumer participation in the development of the individual habilitation plan toward regular surveys and genuine support for consumer groups, conferences, and membership on planning and advisory bodies. **We strongly suggest that program administrators and providers make it a policy to solicit and support the voices of consumers.** Our data even suggest that the quality and clarity of consumer **input** may increase sharply over time.
9. The Pennhurst Study has **not** settled several important questions about system organization, among which are the optimal size of community residences, the reliability and validity of licensing and inspection procedures, the merits of the shift versus live-in staff system, public versus private service provision, and profit versus nonprofit providers. These questions about the characteristics of community services that work best could not be addressed in the Pennhurst work because we were only studying one system. **Comparative studies of systems in several states are necessary to get at these issues scientifically, and we suggest that such studies are needed . Only the federal government can support this kind of interstate research.**
10. Both quantitative and qualitative data indicate that case management is a critical function in any community service system. In the **Pennhurst** case, Judge Broderick issued an order that 30 case managers be hired and assigned to serve about 900 people, resulting in caseloads averaging 30. The quantitative data hint, and our years of discussions with knowledgeable key actors strongly suggest, that case managers must have sensible caseloads to be functional at all. We do not have sufficient comparative data to pin down the optimal number, but the prevailing opinion in our study area strongly suggests caseloads of less than 50.
11. Even with the court scrutiny in **Pennhurst**, case management is a fragile function. In recent years, vacancies in case management positions have gone unfilled for long periods in many counties, sometimes because of hiring freezes, and sometimes for reasons that are not clear. **State and local officials should, if they believe in the value of reliable case management, work to obtain valued status for these positions in civil service hierarchies and salary levels.**
12. **The court, through** its Special Master, also mandated a specific format and an **independent review** process for individual habilitation plans. Qualitative findings indicate early complaints among service providers that the format and the review process were overly rigorous, cumbersome, and slow. Quantitative data, on the other hand, suggest that higher quality plans resulted, and people with this court protection may have received more careful attention and may have displayed more behavioral progress than those without it. On balance, **the research team recommends that state officials should implement simple and consistent formats for individual plans, and either state or local administrators should create a mechanism for periodic independent expert review of such plans.**
13. The Pennhurst Study data have been utilized extensively over the years by Pennsylvania, the counties, individual service providers, and the plaintiffs in the case.

The data have been used for long-range and short-range planning, for selecting individuals with certain characteristics for placement in certain settings, for reporting requirements, and even for projection of costs to serve specific individuals in community settings. We infer from this demand for data that, at least in our area, the existing information systems are primitive at best. The systems that do exist are old in design, often borrowed from mental health or medical applications, and do not contain the kinds of data that would be most useful for planning and evaluating community systems. Most of our experience in other states reveals similar situations. **We therefore recommend that individualized data base construction should be an integral part of service system design and that leadership in this area should come from the state program level.**

## Capacity Building

Apart from the **structure** of community service systems, there are a number of issues that involve gradual processes of strengthening and enhancing services. Building the capacity to perform certain functions will require leadership, technical assistance, training, and confident attitudes among the principal actors. In our years of observing the Pennhurst situation, we have noted a number of key elements in capacity building that may be useful in other states and localities.

1. The Office of the Special Master appointed by the court took on a significant role in capacity building, including recruiting and training case managers, giving technical assistance to service providers, sponsoring workshops, and making public appearances designed to enhance the image of people with mental retardation. This role was, in our view, a positive one, and we infer that activities designed to build capacity in the local service delivery systems are appropriate for court enforcement mechanisms. **The role of compliance monitors can thus evolve beyond that of watchdog toward the active facilitation of exemplary programs and new technologies.**
2. In Pennsylvania there was widespread skepticism about the capacity of community systems to provide adequate care for people with severe or profound impairments. In the **Pennhurst** case, we have seen that the most effective way to build capacity and the belief that it **can** be done is to move those with the most serious disabilities to the community first. The court ordered that special preference for early placement be given to children. Although there were only 61 children at Pennhurst, they had extreme degrees of mental retardation and other handicaps. Because the system was forced to cope, people learned early that very disabled individuals were appropriate for, and able to, benefit from less segregated and smaller settings. **We recommend that deinstitutionalization activities include a means for moving some portion of more disabled institutional residents into the community in the first wave of placements.**
3. Our field experience focused primarily on residential settings, but our strong suspicion from a variety of sources in the study, including the consumers themselves, is that the **next** issue that needs major attention is the availability and quality of day programs. We have **had** the opportunity to study a system in transition from a total institutional model to a **dispersed** community residential model. The data show that Pennsylvania's community residential model has overwhelming advantages, but the data also lead to the **inference that** day programs are not very different from decades-old workshop and adult day care models in other parts of the state and the nation. We suggest that, at least in Pennsylvania, the issue of residential settings has been resolved in favor of the community, but that **day services should be the next target for capacity building through technical assistance and innovative demonstration programs.**
4. The quantitative data on neighbor attitudes suggest another implication for capacity building. As we interpret the data, the strategy of "just moving in" appears to have merit. That is, **when** planning a new community residential setting, if it is legally possible to avoid going to formal hearings and systematically notifying the prospective neighbors, it may be best on balance to do so. Our interviews with neighbors indicated that few neighbors would be opposed **in the absence of outside influences** such as vocal

opposition at hearings or unfavorable media attention. Moreover, the average reaction is negative, but small and short-lived. Finally, citizen opposition to **potential** community living arrangements in their neighborhoods seems to be much stronger than opposition to **actual** residences. **Hence it may be better to avoid direct confrontation with neighbors initially in order to foster the capacity of neighborhoods to assimilate and accept new neighbors with mental retardation over time.**

5. All of our analyses suggest that, in order to ensure the stability of community placements for more disabled individuals, **residential and day program providers must have access to backup services including behavioral and crisis intervention as well as specialized medical assistance.**
6. Our observations of the Pennsylvania system lead us to conclude that growth in community services — especially when accomplished in a short period of time— will alter the character of the local delivery system. Specifically, service agencies will inevitably become more bureaucratic and small providers may have difficulty in making the transition to a more complex system. **In order to protect the flexibility inherent in a system with multiple providers, public mental retardation officials should take steps to guard against too much centralization and uniformity.** Such steps should include timely reimbursement schedules to ensure the cash flow of the small provider as well as the creation of service guidelines that maximize flexibility in the provision of services at the provider level.
7. While some degree of staff turnover in community residential programs may be inevitable and to some extent desirable, our qualitative analyses suggest that too much turnover weakens parental and family confidence and threatens the stability and well-being of clients. **We therefore recommend that steps be taken to improve working conditions (e.g., regularize hours, enrich staff/client ratios), improve compensation, and better equip direct service staff to cope with the needs of more seriously disabled people.**

## The Role of the Courts

Because this was a study of deinstitutionalization that was ordered by a federal court, we have paid close attention to legal issues. Several issues related to the use of litigation to bring about system change have arisen that seem to us to have implications for federal policy, and also in some cases for states and advocates.

1. Our analyses of compliance mechanisms in Pennsylvania and in other states suggest that, to the extent feasible, court monitors and masters should not be given responsibilities **that** mix both programmatic (e.g., traditional state policy functions) and enforcement duties in order to minimize the conflict between the court-appointed official **and the state defendants**, and to **maximize** the degree of "ownership" of court-mandated **reforms by state** and local program officials.
2. **Based on our** comparative analysis of litigation in Pennsylvania and other states, compliance entities such as special masters, should not be involved day-to-day planning activities (e.g., assessment of clients, determination of specific programmatic resources, identification of providers, etc.), but should devote their energies to broad system planning including the establishment of a schedule for key compliance events and the various roles that system participants will play. Involvement in the specifics of planning relieves program authorities from responsibility and disassociates the plan from the ongoing mental retardation system. **The most constructive role that compliance entities can play is to ensure that plans are implemented according to a precise schedule and that resources and funding are attached to each critical milestone.**
- Z. The experience with the Office of the Special Master in Pennsylvania strongly indicates that **funding levels for compliance masters and monitors should be kept at a**



**modest level in order to minimize controversy and to maintain the focus on enforcement and compliance rather than on the compliance mechanism itself.**

4. In the case of **Pennhurst**, despite the fact that the lawsuit clearly polarized groups who might otherwise have been allies, it seems to us that the results—over 600 people moved to vastly enhanced living conditions in six years—would not have been achieved by any other method. **Thus, we suggest that litigation can be a force for the reform of service systems. However, our comparative analyses in other states also suggest that litigation—when aimed primarily at institutional improvement—can hamper the orderly transition to community services.**
5. At the federal level, we suspect that the role of the courts is declining. The U.S. Department of Justice has apparently altered its position on the **Pennhurst** case after eight years, and failed to support the plaintiffs' arguments in the most recent Supreme Court hearing. Moreover, the Justice Department appears in general to be more reluctant to join in actions against public agencies or conditions that may threaten the civil rights of people with handicaps. In addition, our legal analyses suggest that the current Supreme Court is not likely to affirm additional constitutional and statutory rights for people with mental retardation. **We therefore suggest that in the future advocates will concentrate their efforts in state courts, in administrative forums and in the pursuit of regulatory and statutory reform.**
6. The **Pennhurst** court order was just that, an order, and as such was one of only two in the field of broad scale litigation in mental retardation. The fact that it was not a consent decree seems to us to have made the situation more adversarial than other cases analyzed. The absence of a consent decree also contributed to the degree of power and resources that the court conferred on the Office of the Special Master.
7. We infer that consent decrees, where feasible, are more effective tools of reform since they represent a joint statement of purpose by the plaintiffs and defendants. Federal, state, and local officials, as well as advocates, providers, and families, are all interested in the question of whether litigation results in the creation of a privileged class of people who received special attention and resources. In the **Pennhurst** case, this definitely did happen. Even our quantitative data showed more service rendered to, and more behavioral growth among, the class members than among otherwise similar people. Whether this is just seems to us to be a question of whether the wrongs being redressed were serious enough to justify a strong remedy. **Given the long history of failed attempts to improve conditions at Pennhurst, the evidence presented at the trial, and the systemic benefits that accrued to others as a result of the litigation, the remedy in this case appears warranted.**
8. Another concern related to the impact of litigation is whether others are **deprived** of resources that they would otherwise have enjoyed. In Pennsylvania, there is very little evidence to support the assertion that the litigation drew resources away from other areas of the **state**. There **are**, however, a **few** strands of evidence suggesting that non-class members in the Southeast Region might have been affected. Waiting lists for CLAs in the **Southeast Region**, although unreliable and poorly maintained, seem to have increased at a **higher rate compared** to the rest of the state. Reports from some knowledgeable informants also indicate that it has been very difficult for non-class members' families to find day programs in recent years. We cannot, of course, be sure that either of these phenomena was caused directly by the court order. On the other hand, the court order materially benefited other clients in the system when the special requirements for individual plans and monitoring for class members were extended to non-class members who lived with a class member, or who that could be acquired in no other way. It is good policy to try regularly to identify families and consumers with serious complaints, which they may be afraid to voice to service providers, in order to prevent deterioration of conditions and to serve as an early warning system.
4. **We think it is extremely urgent that all users of standards, licensing, or any kind of environmental measures pay close attention to two issues that we have faced continually: independence and reliability.** Here we use the term independence

to mean that any environmental measure of "quality" should be **independent** of the functional level of the people living in the environment. Not one of the program-oriented environmental ratings used in the Pennhurst Study is free of this kind of bias and we suspect that many measures suffer from this shortcoming. This means that a program serving people with more intense needs will automatically receive lower quality ratings. Like the need for measures of intelligence that are free of "culture bias," there is a need for measures of program quality that are free of "functional level bias." **Examination of existing measures and standards should begin immediately, and a national level attempt to develop independent measures should be a high priority.**

5. The second issue, reliability, means that **a program's ratings on any standards or environmental measures should not be influenced by the biases of the site reviewer.** If the measures are unreliable in this sense, then service providers will inevitably realize it after just a few reviews, and are likely to become cynical and treat the entire procedure as a game devoid of meaning. We are not aware of any national level or state level monitoring, licensing, standards, or program audit instruments for which adequate reliability data have been made available. Not only should the users of these instruments **test** for reliability, but they should also take action where necessary by changing the instruments and/or intensifying rater training. In other words, it is time to apply some elementary rules of scientific procedure to the assessment of program quality.
6. Finally, it seems to us that many of the environmental measures, standards, and licensing, inspection tools or program audits that have been developed have contained the assumption, either explicit or implicit, that a program that does well on this review will render good services and produce good outcomes among the people it serves. Perhaps we are past the time when this "outcome assumption" is needed for environmental measures. Many aspects of the living situation are related to basic rights, others involve simple sound management, others involve comfort and safety, and not all need to produce growth and development. We have worked very hard to test the "outcome assumption" for a variety of environmental measures, and have found only relatively weak correlations and hints of association. We are beginning to consider the idea that, because outcomes themselves are known to be reliably and economically measurable, perhaps new approaches to environmental measures and standards will abandon the "outcome assumption." **Measures and standards should instead focus on simple, observable, reliable facets of the setting without making the "outcome assumption," but rather require (or even collect) outcome and service data for every individual in the setting. In fact, that is the direction this research team would recommend for the future.**
7. Recently, we have observed changes in court-ordered services that are characterized by a decline in staff commitment and understanding of the ideology that brought about the creation of community services. Instead, some staff increasingly regard their jobs as a set of tasks unrelated to the larger aims of normalization and habilitation. **As a result, we strongly suggest that the expansion of services should be accompanied by a redoubled effort to communicate program values and ideology in order to ensure that service approaches do not become over-bureaucratic, routine, and standard.** Without the continued orientation of staff to the norms that generated the development of institutional alternatives, system administrators and providers run the risk of recreating custodial care in the community.

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